End of Life Care

Setting the context of support for people nearing the End of Life.

Strategy and policy initiatives

Why consider policy and strategy? How is this of relevance to the care we give?

- End of Life Care Programme
- End of Life Care Strategy

- Gold Standards Framework
- Preferred Priorities of Care

- Advanced Care Planning e.g. DNACPR
- Rapid Early Discharge
- 'Difficult Conversations'
- Partnership working with service users, their families and carers

The current context: Statement from DH 25/03/2013

* Every year, around half a million people die in England, and two thirds of them are people over 75. Most of these deaths come after a period of long term illness such as heart disease, cancer or dementia.

* Although everybody has their own idea of what a 'good death' is, for most people it would involve being without pain, in a familiar place with close family or friends and being treated with respect. 75% of people say they would prefer to die at home. Recently, the number of people dying at home in has increased (42% in 2011), but over half of deaths still occur in hospitals.

* In a 2011 survey, 43% of bereaved people said they thought that care for their loved one in the last 3 months of life was excellent or outstanding. But 24% said it was fair or poor - too many people aren't getting high quality care at the end of their life.

DH 25/03/13 Recent Actions

Planning the best possible care

* In 2012, we published the first NHS Mandate, which sets out what the NHS must achieve for patients. It states that the NHS should give the highest standards of care - not just treatment - particularly for older people and at the end of people's lives.
* In 2013, we gave responsibility for planning how to provide end of life care services to NHS England.

Evaluating the success of our approach

* Since 2008, we have taken a 'care pathway' approach to providing end of life care. This means planning and providing the right kind of care at every stage. It involves:
* identifying people approaching the end of their life and involving them as much as they want in plans around their death - including their preferences for care
* planning, co-ordinating and providing high quality care
* managing care and support in the last days of a person's life, at the point of death and beyond
* providing support to carers, including after the person they have cared for has died
* In 2013, we will assess how successful our care pathway approach has been in providing people with the right choices for end of life care. This evaluation will show how close we are to being able to offer a formal choice for someone to die in the place where they live.

Policy initiatives in end of life care

* NICE Cancer Guidance 2004
* End of Life Care Strategy 2008
* National End of Life care programme 2008-13
* Carers at the heart of 21st-century families and communities 2009
* Recognised, valued and supported: Next steps for the Carers Strategy�2010
* Supporting people to live and die well: a framework for social care at the end of life 2010
* NICE quality standard for end of life care for adults (2011).

DH End of Life Care Strategy July 2008

* Promoting high quality care for all adults at the End of Life

* The End of life care strategy aims to improve the provision of care for all adults at the end of life, and their families and carers.

* "How people die remains in the memory of those who live on " (Dame Cicely Saunders)

* The age profile of people at the time of death and the relative frequency of different causes of death has changed. The place where people die has also changed markedly over the past century with most deaths no longer occurring at home but in hospital.

* As a society we do not talk openly about death and dying. Relatively few adults, including older adults, have discussed their own preferences for care. Health and social care staff often find it difficult to initiate discussions with people about the fact that they are approaching the end of their life.

Key areas addressed by the strategy

* Raising the profile of end of life care and to change attitudes to death and dying in society.
* Strategic commissioning of services
* Identifying people approaching the end of life
* Care planning: available to all who have a legitimate reason to access it (e.g. out of hours and emergency services).
* Coordination of care: recommended that PCTs create locality-wide registers for people approaching the end of life,
* so that they can receive priority care.
* Rapid access to care
* Delivery of high quality services in all locations
* Last days of life and care after death
* Involving and supporting carers

The need for policy development to support EoLc: Changing demographic & cultural landscape

* Changes to the demographic and cultural
* landscape have ensured that end of life care is
* afforded central importance in public policy: the
* fastest-growing population group is people aged
* over 85. We are seeing a prolonged period at
* the end of life in which levels of frailty, illness
* and disease are likely to increase, sometimes
* shading imperceptibly into the acute dying
* phase. Thus, quality of life in old age also
* extends to quality of dying.
* Services also need to
* be appropriate to the diverse communities that
* characterise the UK today.

* On average, people have 3.5 admissions to hospital in their last year of life, spending almost 30 days in bed in hospital

Policy drivers continued

* People with serious illnesses and congenital
* conditions are living longer, while the numbers
* of those living with Alzheimer's and other forms
* of dementia are increasing. 'Survivorship' when
* living with serious and life limiting illness is an
* increasingly important dimension to end of life
* care. However, advances in medical treatments
* mean that many of these individuals can be
* cared for and die at home, if the right package
* of support and care is in place, including out of
* hours and 24/7 care services.

Further Policy drivers

'Family' in the 21st century is a complex concept: essentially, it can be whatever the individual wants it to be. Family caring roles are varied and traditional roles may be reversed, with, for example, an adolescent caring for a parent or a learning-disabled adult caring for an older relative.

Assumptions about support from extended family in black and minority ethnic (BME) communities may be inaccurate in the context of greater social and geographical mobility.

Coalition Government policy aims

Government policy of supporting people to remain in their own homes for as long as they might wish. This includes supporting people to live and die in the place of their choice. It is acknowledged, however, that the current system of care and support is unsustainable. Key thrusts in the agenda to transform social support, such as personalisation, re-ablement and workforce development, offer significant opportunities for improving the care that individuals and their families receive at the end of life, through a focus on facilitating autonomy, choice and control.

Why?

Back to the beginning

* What do we mean by End of Life Care?

* Which types of people are the primary focus of EoL policy initiatives?

Living and dying with dignity

EoLc : a definition

* People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

* advanced, progressive, incurable conditions

* general frailty and coexisting conditions that mean they are expected to die within 12 months

* existing conditions if they are at risk of dying from a sudden acute crisis in their condition

* life-threatening acute conditions caused by sudden catastrophic events.

* Given this, any palliative care within the last 12 months of life is regarded as end of life care (GMC 2010)

Palliative care: a definition

* "…the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments."

(NICE 2004)

Development of models of service delivery to address:

* Physical symptoms such as pain, breathlessness, nausea and increasing fatigue, people who are approaching the end of life may also experience anxiety, depression, social and spiritual difficulties.

* The proper management of these issues requires effective and collaborative, multidisciplinary working within and between generalist and specialist teams, whether the person is at home, in hospital or elsewhere.

* Information about people approaching the end of life, and about their needs and preferences, is not always captured or shared effectively between different services involved in their care, including out of hours and ambulance services.

Ensuring Quality in EoLc?
NICE Quality Standard for EoLc for adults QS13

* quality standard covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. This includes adults who die suddenly or after a very brief illness. The quality standard does not cover condition-specific management and care, clinical management of specific physical symptoms or emergency planning and mass casualty incidents.

* It sets out markers of high-quality care for adults aged 18 years and older with advanced, progressive, incurable conditions; adults who may die within 12 months; and those with life-threatening acute conditions. It also covers support for the families and carers of people in these groups.

* quality standard describes high-quality care that, when delivered collectively, should contribute to improving the effectiveness, safety and experience of care for adults approaching the end of life and the experience of their families and carers

* http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13

Outcome(s) for people approaching the end of life:

* The care that people approaching the end of life receive is aligned to their needs and preferences.

* Increased length of time spent in preferred place of care during the last year of life.

* Reduction in unscheduled care hospital admissions leading to death in hospital (where death in hospital is against their stated preference).

* Reduction in deaths in inappropriate places such as on a trolley in hospital or in transit in an ambulance.

End of Life Care Strategy Fourth Annual Report - Progress (DH 2012)

* To tackle the taboo on discussing death, the Strategy proposed "A national coalition to raise the profile of end of life care and to change attitudes to death and dying in society". The National Council for Palliative Care has set up the Dying Matters coalition. From a standing start in 2009 it now has more that 20,000 members. This year's Awareness Week has been evaluated as reaching more than 170,000 people through events and activities run by Dying Matters members, while the Dying Matters website received record numbers of visitors, with almost 100,000 page views - an increase of 230% on last year's awareness week. www.dyingmatters.org

* "Care plans, including the person's preferences, wishes and views on resuscitation, should be available to all who have a legitimate reason to access them … Holding the plan electronically will facilitate this…" Electronic Palliative Care Coordination Systems (EPaCCS for short)

* "…The Department of Health will commission the development of an End of Life Care Intelligence Network." The National End of Life Care Intelligence Network took off in 2010.

* http://www.endoflifecare-intelligence.org.uk/home

End of Life Care Strategy Fourth Annual Report (DH 2012) Place of death

Percentage of deaths by place-of-death category, England, 2008-2011.
ONS Death Registrations data
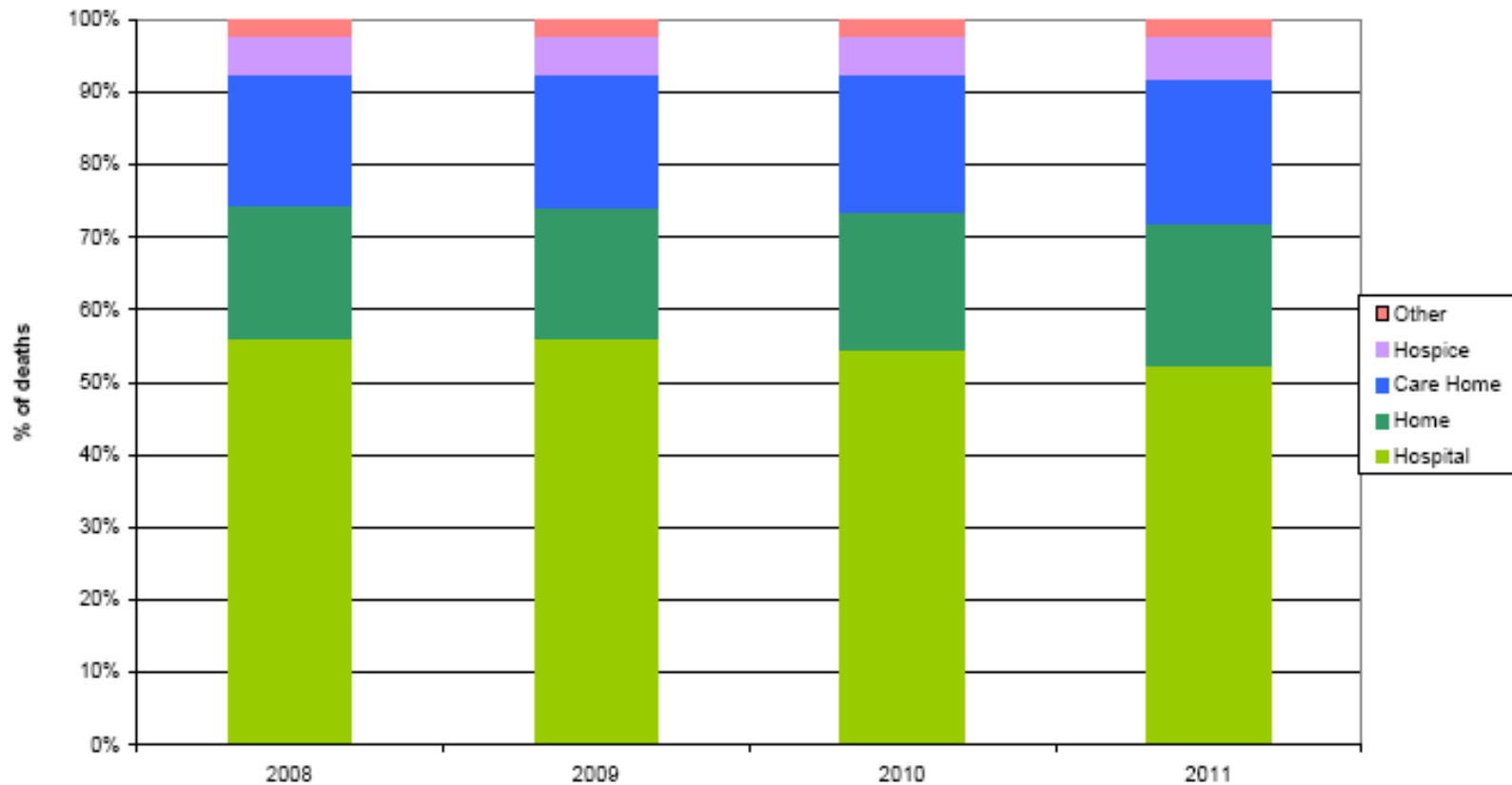
Palliative care Funding Review 2011

"There has also been strong support for the [Palliative Care Funding] Review's recommendation that 'once a patient reaches the end of life stage, and is put on the end of life locality register, all health and social care should be funded by the state and be free at the point of delivery'. We think there is much merit in providing free health and social care in a fully integrated service at the end of life."

So in summary:

* Policies outline what is considered important in an aspect of service provision and thus what should be commissioned for and funded, how services should be developed and implemented, how they should be evaluated and subsequently paid for (QOF Quality Outcomes Framework) & (QIPP Quality, Innovation, Productivity and Prevention) www.evidence.nhs.uk/qipp

* Policies are value based

* Policies are shaped by social, political, economic and public health factors

* Policies provide the framework for health professional engagement in the provision of care and therapies

A global perspective

* quality end-of-life care should be seen as a global public health and health systems problem. It is a global problem because 85 % of the 56 million deaths worldwide that occur annually are in developing countries. It is a public health problem because of the number of people it affects, directly and indirectly, in terms of the well being of loved ones, and the large-scale, population based nature of some possible interventions. It is a health systems problem because one of its main features is the need for better information on quality end-of-life care.

* Lack of systematic data on capacity for delivering quality end-of-life care in developing countries.

* Possible objection to improving end-of-life care in developing countries; many deaths are preventable and reduction of avoidable deaths should be the focus of attention.

Quality care at the end of life in Africa

Each year about 0.5% of the total population in Botswana, Ethiopia, Tanzania, Uganda, and Zimbabwe die from HIV/AIDS or cancer. The members of a WHO project to improve palliative care in these countries discuss their work. The greatest needs of terminally ill patients were for adequate pain relief, accessible and affordable drugs, and financial support to counter the loss of income of both patient and family caregiver. Special emphasis should be given to home based palliative care provided by trained family and community caregivers to counteract the severe shortage of professional healthcare workers